MFTD Waiver Families

Support for Families of Children
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Public Comments on the Illinois Path to Transformation 1115 Waiver July 2014

MFTD Waiver Families represents children and young adults who participate in the Medically Fragile, Technology Dependent (MFTD) 1915(c) waiver in Illinois. We are a support and advocacy group comprised of about one-quarter of the families in this waiver. Children and young adults in this program are medically fragile and use complicated medical technologies including ventilators, tracheostomies, and central IV lines. 95% of children currently in the program require hospital-level care 24 hours per day, as certified by the state of Illinois.

Because the population of children in the MFTD waiver differs so greatly from the average Medicaid consumer, we suggest removing the MFTD waiver from the 1115 Demonstration Waiver, allowing the MFTD waiver to remain a separate 1915(c) waiver. This will best serve the unique needs of this population, while continuing to comply with all federal Medicaid and disability laws.

If the MFTD population is not removed from the 1115 Demonstration Waiver, there are many alarming problems that will need to be resolved in order to provide appropriate services and care for these children. As it stands, the proposed 1115 Demonstration Waiver could severely limit eligibility and services for children and adults with medical technology. The resultant changes to the program could easily violate the Americans with Disabilities Act and lead to *Olmstead*-related litigation.

Potential problems include the following:

1) Private duty shift nursing (>8 hours per day on a daily basis) is unavailable to individuals who require it, because skilled nursing care is limited to 365 hours per year in the 1115 Waiver.
2) Because the state is requesting a waiver of amount, scope, and duration rules, there is no guarantee that EPSDT-required services would be preserved without limitations.
3) There is no legal pathway in the 1115 Waiver granting children from middle class families access to Medicaid by allowing the use of institutional deeming rules.
4) The 1115 Waiver fails to include provisions that would address current EPSDT violations occurring in the MFTD waiver, such as a failure to provide state-approved nursing care hours.

5) Waiting lists will be permitted in the 1115 Waiver, even though there have never been waiting lists for the MFTD waiver. There is no methodology in the application for prioritization of the waiting list, possibly preventing children on ventilators or other medical technologies from leaving the hospital.

These problems with the 1115 Demonstration Waiver, along with further implementation issues relating to assessment and individuals budgets, could lead to cuts in home and community based services for this population, and are likely to lead to increased use of institutionalization, specifically hospitalization. This contradicts the stated purpose of the 1115 Demonstration Waiver, as well as the Americans with Disabilities Act.

Private Duty Shift Nursing

Individuals with ventilators, tracheostomies, and central IV lines typically require hospital-level care at all times, and currently receive about 12-18 hours of private duty shift nursing per day through the MFTD waiver. **The Final Application for the 1115 Waiver limits nursing care to 365 hours per YEAR, thereby failing to provide a true option for private duty shift nursing.**

The types of home nursing care offered in the 1115 Waiver include the following:

1) Nursing (CNA) [p. 14 and defined on p. 77]: "Service provided by an individual that meets Illinois licensure standards for a Certified Nursing Assistant (CNA) and provides services as defined in 42CFR 440.70..."
2) Intermittent Nursing [p. 14 and defined on p. 77]: The service definition here is somewhat unclear, but the term "intermittent nursing" is defined by the Medicare Manual, chapter 7, section 40.1.3, as, "skilled nursing care that is either provided or needed on fewer than 7 days each week, or less than 8 hours each day for periods of 21 days or less…"
3) Skilled Nursing [p. 14 and defined on p. 78]: Nursing services provided by an RN or LPN, but, "There is a State fiscal year combined maximum of 365 hours of service by a registered nurse and 365 hours of service by a licensed practical nurse."

Private duty shift nursing, which is 8 or more hours per day of nursing that is required on a daily basis, does not fit into any of these categories.

Illinois' Nurse Practice Act bars CNAs from providing care for individuals with medical technology, and even forbids them from administering medications, therefore making the "Nursing (CNA)" services unavailable for this population.

Intermittent nursing, as typically defined by CMS, is not shift nursing, but rather intermittent visits or short-term nursing. Most children require more nursing care than a 1-8 hour intermittent visit that occurs once or twice a week. Virtually all require nursing for more than 21 days in a row. Their needs are continuous and ongoing.

Skilled nursing could in theory be used as shift nursing, but the listed maximum of 365 hours per year precludes care for individuals with ongoing, daily needs.

We alerted the state in two of the stakeholder meetings that daily private duty shift nursing was not an included service in the 1115 Demonstration Waiver. We were told that there were issues with the definitions, and this was simply an oversight. However, in the Final Application, the definitions appear word-for-word from the draft.

The state's response to public comments on the 1115 Waiver incorrectly states that either Intermittent or Skilled Nursing could be used for shift nursing. **But the 1115 Waiver places a 365 hours per year maximum on skilled nursing care, meaning a child currently served by the MFTD waiver could only receive nursing for about 23 days per year.** This is clearly insufficient for any individual with significant medical technology. The definition for Intermittent Nursing continues to be unclear, but under all standard uses of the term, this category would not include daily, longterm private duty shift nursing.

Because the state of Illinois has a long history of denying private duty shift nursing to people with medical technology, we believe that private duty shift nursing may have been left out of the 1115 Waiver intentionally. Illinois has failed to provide this service to adults for years, has threatened to stop providing nursing to children, and has faced repeated *Olmstead*-related litigation on the subject.

Until recently, adults in Illinois did not have access to much—if any—private duty nursing. Illinois' state plan does not provide any ongoing private duty shift nursing to adults. Some home nursing is available through various 1915(c) waiver programs for adults, but these programs all limit nursing hours to less than the cost of a nursing home, which is typically less than 8 hours of care per day. This policy ultimately led to multiple *Olmstead*-related individual lawsuits, as well as the class action suit *Hampe v. Hamos*. The latter was recently settled, and provides private duty shift nursing in appropriate quantities for individuals over the age of 21 who have aged out of the MFTD Waiver. This settlement unfortunately excludes individuals who began relying on medical technology after the age of 21, meaning many adults still do not have access to appropriate levels of private duty nursing care.

Children have also been targeted. In February 2012, Director Julie Hamos of the Department of Healthcare and Family Services recommended eliminating the MFTD Waiver entirely, thereby curtailing access to Medicaid and private duty nursing care to all but low-income families. The state did back off from this approach, but then proceeded to propose a plan that limited the program by income, imposed copays, reduced the level of care, and—perhaps accidentally—made 95% of children in the MFTD waiver ineligible for the new program. After a lawsuit, media coverage, and negotiations with CMS over a two-year period, Illinois finally returned the MFTD waiver to its original state with minimal changes.

While the MFTD waiver was preserved, Illinois continues to target children with private duty nursing hours. Beginning in 2009, the state analyzed the children in the program, cutting off services for as many as 100 children and reducing hours for many more. These actions led to a more than 1000% increase in fair hearings and appeals. In 2013, the state specifically contracted with outside agencies to review each child's hours and reduce them based not on personal physician recommendations as required by EPSDT, but on standardized unvalidated assessment tools (created without physician input) that often fail to capture the unique needs of these children. Children new to the program will no longer even receive private duty nursing hours, but will instead be awarded a "budget" to spend on home care, which seems like a potential violation of EPSDT and amount, scope, and duration rules.

This pattern of denying private duty shift nursing to children and adults with medical technology is too obvious to deny. With this history, it seems likely that the exclusion of private duty shift nursing from the 1115 Demonstration Waiver is intentional.

If private duty shift nursing without limitation is not provided through the 1115 Waiver, individuals with ventilators will not be able to live at home. **People who currently receive private duty shift nursing through waivers will see their nursing reduced to a maximum of one hour per day, a reduction that will force them out of their homes and into hospitals and institutions.** This threatened institutionalization is likely a violation of the Americans with Disabilities Act as clarified by the *Olmstead* decision. It is most surely a violation of the *Hampe v. Hamos* settlement decree for young adults who have aged out of the MFTD waiver, though it is also possible that rolling the MFTD waiver into the 1115 Demonstration Waiver could make this settlement decree moot.

By not including private duty shift nursing in the 1115 Demonstration Waiver, Illinois is actually cutting benefits to individuals currently in 1915(c) waivers. Illinois is introducing further institutional bias into its Medicaid program, and threatening forced hospitalization on individuals with ventilators and other medical technologies.

While children should be shielded from the exclusion of private duty shift nursing by EPSDT mandates, the requested waiver of amount, scope, and duration rules could possibly limit EPSDT services, including private duty nursing.

EPSDT Issues

During stakeholder meetings, representatives of the state and its contracted entities verbally stated that EPSDT-required services would be maintained without limits. These representatives also include these reassurances in their responses to public comments. However, there is no mention as to whether EPSDT will or will not be preserved in the actual 1115 Waiver Application.

In the 1115 Waiver Application, the state requests a waiver of amount, scope, duration, and comparability rules (p. 53), that includes a plan, "to allow the State to place service cost maximums on HCBS." **While the state maintains on p. 13 that state plan benefits will not be changed, by allowing budgets with cost maximums, the state could conceivably reduce EPSDT services to some or all children, either by designating certain children as not EPSDT-eligible, or by determining that the requested waiver of amount, scope, duration, and comparability supercedes EPSDT rules.** 1915(c) rules ensure that children currently in the MFTD waiver receive full EPSDT benefits, but 1115 Demonstration Waivers do not have the same requirement, and this type of waiver can be used to reduce or eliminate EPSDT benefits, such as in the Oregon Health Plan.

While we hope the state is committed to maintaining EPSDT services without limitations, we would like to see reassurance in the actual written 1115 Waiver that EPSDT services will be continued without limits, and that all children under the age of 21 eligible for the 1115 Demonstration Waiver will remain EPSDT-eligible.

Eligibility for Children Who Qualify Under Institutional Deeming Rules

Currently, children of all family incomes in Illinois qualify for the three children's 1915(c) waivers (MFTD Waiver, Children's Support Waiver, and Children's Residential Waiver) because these programs use institutional deeming rules to determine eligibility. These rules count only the child's income, and not the family income, when determining financial eligibility.

The state has not requested a waiver allowing the use of institutional deeming rules with the 1115 Demonstration Waiver. Without this type of waiver, we do not see a consistent, legal method of access for children whose families do not qualify financially for Medicaid.

It is critical that children from middle class families remain eligible for services because private insurance typically does not—and is not required to—cover private duty nursing and other essential services these children need to avoid institutionalization. Private duty nursing is not considered part of the required Essential Health Benefits insurance plans must cover. Despite repeated requests from families and some legislators, Illinois has not required insurers to cover private duty nursing, and most choose not to do so, or limit the benefit substantially. For example, many insurance plans only cover 300-400 hours per year of private duty nursing, which is less than most children need in one month. Other plans cap coverage at $1000 per month, which only covers a few shifts. Even those that claim to cover private duty nursing usually only do so for short periods of time when a child is first released from the hospital, usually six months to a year.

Without insurance coverage of private duty nursing, families must rely on Medicaid if they want their children to live at home. Unfortunately, private duty nursing is expensive, and even wealthy families have difficulty covering the costs. On average, it

costs $102,062 per year for private duty nursing care for each child in the MFTD waiver. Even a family earning 1500% FPL with insurance would be unable to pay for private duty nursing out-of-pocket. These children cannot be cared for at home without receiving Medicaid wrap-around coverage, and most would have to be hospitalized—at three times the cost to the Medicaid program.

We must remember that Medicaid waivers were originally intended exactly for children like those in the MFTD waiver. Katie Beckett came from a middle class family with two working parents and medical insurance. Even so, her family had no way to pay for the extraordinary level of care she required at home. Medicaid waivers were created to allow children from middle class families to gain eligibility to Medicaid by employing institutional deeming rules for eligibility. **Eliminating a pathway to Medicaid eligibility for middle class families with extraordinary circumstances would be straying away from the original purpose of Medicaid waivers, and would potentially violate the Americans with Disabilities Act.**

In the 1115 Waiver, the state does include in its list of eligible groups both "HCBS waiver enrollees eligible under institutional rules," and "Medically Needy Aged, Blind or Disabled persons, pregnant women and children." These designations would include a tremendous number of individuals if applied universally, which suggests the state plans to create specific eligibility rules for those people who do not qualify financially. **Because the state has not specified what those rules may be, we are uncertain at this time whether children in the MFTD waiver would continue to qualify for the 1115 Demonstration Waiver. It is possible that the state could restrict eligibility to only individuals below a certain income cap, or only children with certain conditions.**

Illinois has in the past tried to restrict eligibility to the MFTD waiver, including placing an income cap on the program in 2012, which was ultimately repealed by legislators. Without a clear mechanism in place, we are concerned that these types of caps could be implemented in order to reduce the number of children eligible for the program.

We would like clarification on the legal mechanism that will be used to ensure children who currently qualify for waivers under institutional deeming rules will continue to qualify under the 1115 Waiver, despite family incomes that exceed standard maximums.

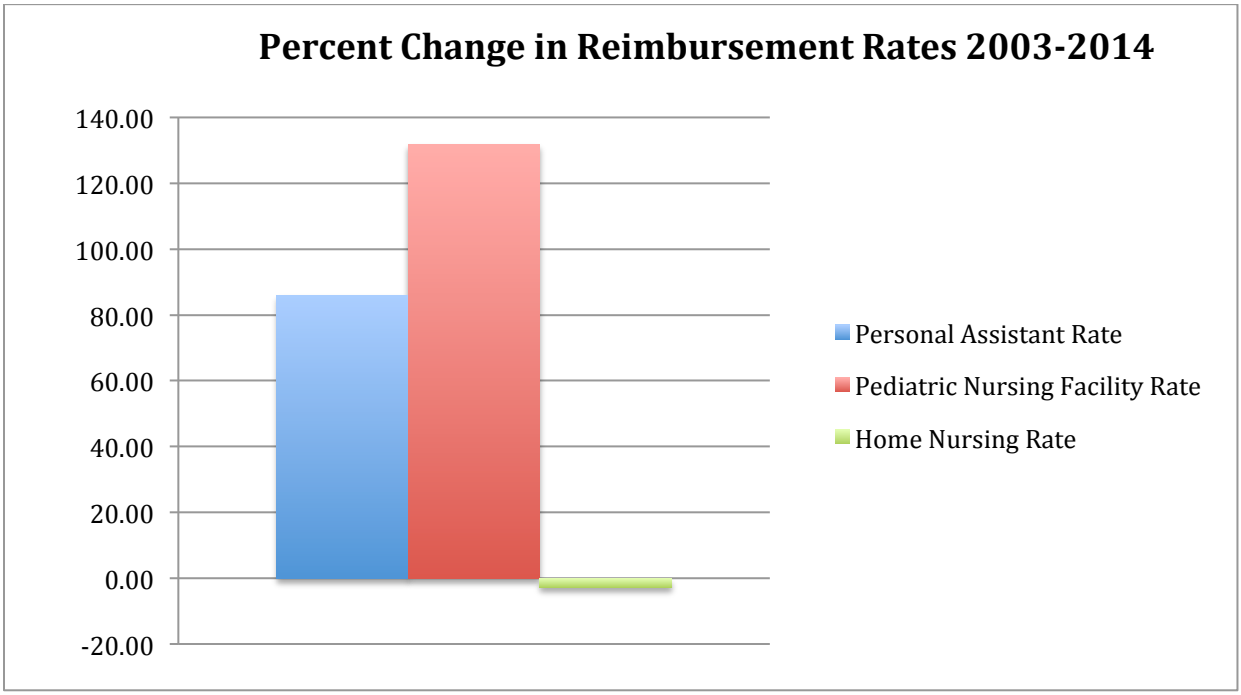
Current EPSDT Violations

The state of Illinois is currently not meeting its EPSDT burden to provide all medically necessary and state-approved services to children with medical technology. Despite multiple suggestions from MFTD Waiver Families to address this issue, Illinois chose to include few of these in the 1115 Application. As such, there is no expectation that Illinois will be able to meet its EPSDT burden.

Private duty nursing has not been made available to many children due to reimbursement rates that have not been increased in a decade, and were even

reduced in 2012. The last data we have available demonstrates that only 60% of state-approved nursing shifts are being staffed, primarily due to low nurse pay. Parents are being forced to quit their jobs, further stressing the Medicaid safety net, because nursing is not being provided. Nurse pay needs to be differentiated appropriately, and raised considerably to account for medical inflation.

While Personal Assistant pay in Illinois has been increased 86% in the last decade, Home Nurse reimbursement has actually been cut 2.7%. Similarly, after increases of 3.59% in 2003, 3% in 2006, and 2.2% in 2008, reimbursement for children on ventilators living in skilled nursing facilities increased more than 100% due to recent legislation, while reimbursement for children on ventilators living at home was cut 2.7%. This demonstrates further institutional bias in Illinois, and a pattern of neglect of the neediest children, simply because they are more expensive.



In addition, Illinois has instituted a new verification system for anyone receiving private duty nursing, using an external corporation to override a physician's order for medically necessary services. In the contract with this company, KePro, Illinois has budgeted for 500 appeal hearings and 200 court cases, suggesting they expect numerous children to either be dropped from the program or have their nursing care hours reduced. The only way for this verification system to be profitable is if the state plans to use it to cut back medically necessary hours guaranteed by EPSDT.

Illinois also plans to limit prescriptions to 4 per month for children beginning this year, which seems a clear violation of its duty under EPSDT to arrange services and ensure they are available to children.

Unfortunately, Illinois has a long history of violating EPSDT rules. The important lawsuit *Memisovski v. Maram* resulted in a settlement that forced Illinois to publicize EPSDT services, increase primary medical/dental service usage, and increase pay to pediatric providers. Despite this lawsuit, Illinois continues to restrict EPSDT services. Multiple other lawsuits, including recently filed litigation alleging Illinois restricted EPSDT-required mental health services to children, paint a clear picture of ongoing attempts to side-step EPSDT.

Illinois needs to develop innovative programs to meet its EPSDT burden, especially nurse training and support. Nurse pay needs to be raised considerably, to appropriate and fair market levels. We also strongly suggest that Illinois invest in long-term strategies for children with complex medical issues, including paying for concurrent palliative care services, in-home physician services, telemedicine services, and third party liability coordination. Similar programs in Boston have saved $1 million for children on ventilators alone, and millions more throughout Massachusetts' Medicaid program.

Waiting Lists

The request for a waiver of reasonable promptness (p. 53) indicates that waiting lists will be a part of the 1115 Waiver. While the 1115 Waiver discusses the current waiting lists for individuals with developmental disabilities, it does not mention how new applicants with serious medical issues, such as newborn children on ventilators, will be placed on waiting lists.

We would like clarification as to whether all children who are presumptively eligible for the program will be afforded immediate access to the program, and if not, what type of system will be used to prioritize access. **We encourage a system of reserved spots for children with medical technology to ensure access is always available for this population.** We also want to guarantee that the wider eligibility pool of both children and adults will not impact the ability of children on medical technology to obtain urgently needed services without delay. It is in the state's best financial interest to move children from expensive hospital environments into home settings as expeditiously as possible.

Conclusion

Individuals with medical technology require extensive services and supports in order to live in the community, which is their right under the Americans with Disabilities Act. We suggest removing this population from the 1115 Demonstration Waiver and continuing appropriate coverage through a 1915(c) waiver, due to the unusual nature and magnitude of their needs.

If this population is included in the 1115 Demonstration Waiver, changes will need to be made in order to care for these children safely and legally without the proposed or potential cuts in services and eligibility.